

NSW Government response to NSW Legislative Assembly Committee on Law and Safety inquiries into donor conception

The NSW Legislative Assembly on Law and Safety conducted two inquiries and released two reports on donor conception. *Inclusion of Donor Details on the Register of Births* ("the first report") was released in October 2012 and relates to how the details of donors are recorded.

Managing Donor Conception Information ("the second report") was released in October 2013 and focuses on the broader issues of how donor information is collected and accessed, and what supports should be in place for people accessing this information.

The Government responded to the first recommendation of the Committee's first report in April 2013. At that time, the Government indicated it would await the release of the Committee's second report before responding to the remaining recommendations in the first report.

This response outlines the Government's position on the other five recommendations in the first report, as well as all the recommendations of the second report.

The Government recognises how important it is for donor-conceived people to be able to access information and learn about their biological origins. International law enshrines the rights of the child, including the right of a child to know his or her parents and preserve his or her identity. These rights are supported by the *Assisted Reproductive Technology Act 2007* (NSW), which ensures that all donor-conceived children born after 2010 have the right to access information about their genetic history.

The findings of the Committee make clear that the management of donor information, particularly information that relates to donor-conceived people born before 2010, needs to be done in a sensitive, and considered manner. The changes that the Government will be enacting in response to the Committee's recommendations are a significant step in fulfilling the needs of donor-conceived people to know their genetic heritage whilst respecting the wishes of those donors who donated under a different system to maintain their anonymity.

The Government supports all of the outstanding recommendations made by the Committee in its first report. Legislative amendments will be proposed to enable the Registrar of Births, Deaths and Marriages to record donor-conceived status in the register of births. These legislative amendments will also provide that an addendum, indicating that further information is available, should be attached to birth certificates issued to adults who are recorded as donor-conceived. The donor-conceived adult will then be able to seek that further information by applying to the Central Register. As recommended by the Committee, gamete donors' details will continue to be held on a separate donor register (the Central Register), and will not be included on the register of births or birth certificates.

The Government agrees that participants in private (non-medical) donor conceptions should be permitted to voluntarily register their details on the Voluntary Register, and will also be bringing forward legislative amendments to enable this to occur.

In response to the Committee's second report, the Government supports access to pre-2010 donor conception information on the basis of the consent-release model recommended by the Committee. This model strikes a balance between the needs of donor-conceived people to learn about their biological origins, and the wishes of anonymous donors who donated under a different system. Under this model, non-identifying information may be released without consent, but identifying information may only be released with the donor's consent.

The Central Register will continue to be managed by NSW Health. The Government recognises that specialist services are required to sensitively manage this information, and will be providing additional support services and conducting an awareness-raising campaign associated with the Register. Although the Government does not support the recommendation to establish a new stand-alone agency to manage the register of donor conception information, it recognises that the rationale behind this recommendation was to ensure access to donor information is facilitated by people with specialist skills who understand the issues particular to donor conception. NSW Health will consult with all stakeholders, including donors, donor-conceived people and their parents, to design a system of information access that draws on the strengths of similar schemes (e.g. access to adoption information) and is streamlined, flexible and responsive to their needs.

The Government will also consult with ART providers and medical professionals on how the consent-release model for pre-2010 information is implemented. The Government will initially consult ART providers and medical professionals on the recommendations that seek to ensure that: (a) pre-2010 donor conception information is securely and accessibly stored and managed; and (b) donor-conception information is not destroyed, tampered with, or falsified. The consultation with ART providers will address the prospect of requiring ART providers to collate and submit pre-2010 donor conception information held by them to the Central Register. The consultation will inform the way in which the collation process should be undertaken if it is to proceed. If collation is not to proceed, NSW Health will investigate other options to make this information more accessible to donor-conceived people and how ART providers could give effect to the consent-based regime for access recommended by the Committee and supported by Government. This will be the subject of further consultation with a full range of stakeholders, including donors, donor-conceived people and their parents. Any legislative amendments to implement the access provisions, whether the material is collated and stored under centrally or remains with ART providers, will also be the subject of consultation with stakeholders, which NSW Health will lead.

Recommendation	Government response
First Report - Inclusion of donor details on the register of births (October 2012)	
<p>1. That the NSW Government work with state and territory governments to develop a nationally consistent system for the registration, management and release of information in relation to donor conception.</p>	<p>The NSW Government has already expressed in-principle support for this recommendation, but noted that the regulation of such matters in other states and territories is ultimately a matter for those jurisdictions.</p> <p>This issue has previously been an item on the Standing Council of Law and Justice's agenda (made up of the Attorneys-General of the Commonwealth and States and Territories and the Minister of Justice of New Zealand) with little progress made. The NSW Government will continue to support this recommendation.</p>
<p>2. That the Attorney-General introduce legislation to provide that, if a birth registration statement specifies that a child was donor conceived, the Registrar of Births, Deaths and Marriages is to note that the child was donor conceived in the entry about that child's birth on the register of births.</p>	<p>Supported. The Government agrees that although donor details should not be recorded on the register of births (see recommendation 5, below), the Registrar of Births, Deaths and Marriages can play a role in facilitating the disclosure of, and access to, this information. It will therefore propose amendments to the <i>Births, Deaths and Marriages Registration Act 1995</i> to implement this recommendation.</p>
<p>3. That the Registrar of Births, Deaths and Marriages is to issue an addendum on a separate page, indicating that further information is available, when a donor conceived individual aged 18 or over applies for a birth certificate.</p>	<p>Supported. The proposed addendum will encourage openness and facilitate the disclosure of donor-conception information, but also protect the privacy of donor-conceived individuals.</p>
<p>4. That the Registry of Births, Deaths and Marriages and the Ministry of Health inform stakeholders of the changes to birth registration statements and birth certificates, through measures including agency websites and brochures.</p>	<p>Supported.</p>
<p>5. That gamete donors' details continue to be held on a separate donor register (the ART Central Register), and not be included on the register of births or birth certificates.</p>	<p>Supported. The Government agrees with the Committee that the purpose of the births register and birth certificates is to record a child's legal parents. Neither is intended to be a record of the child's genetic origins. To include donor details on the birth register or birth certificates would create confusion about the rights and responsibilities of parents and donors; would be inconsistent with other jurisdictions; and would also limit the privacy of donor-conceived individuals.</p>

Recommendation	Government response
<p>6. That the Minister of Health:</p> <p>a) Implement processes to enable participants in private donor conception arrangements to voluntarily register their details on the voluntary register;</p> <p>b) Publicise information on voluntary registration of details of participants in private arrangements on the Ministry of Health website and through public awareness material such as information brochures.</p>	<p>Supported. Donors and individuals conceived as a result of ART treatment involving donor conception prior to 1 January 2010 may voluntarily place information about themselves on the Voluntary Register. It is in the interests of donor-conceived people that participants in private donor conception arrangements also be enabled to voluntarily register their details.</p> <p>It is noted that this will require amendments to the ART Act, not just the implementation of new processes. The provision for registering private arrangements on the Voluntary Register will be highlighted in the advertising campaign to be carried out by NSW Health pursuant to recommendation 11 of the second report.</p>

Recommendation	Government response
Second Report - Managing donor conception information (October 2013)	
<p>1. The Committee recommends that the Attorney General establish a new agency to manage a Register of donor conception information and that this agency also assume responsibility for providing support to those involved in donor conception.</p>	<p>The Government supports the register of donor conception information being managed by the one agency. NSW Health will continue to manage the register and will coordinate support services, including an intermediary and support service for donors, donor-conceived people and recipient parents if a match occurs (that is, where identifying information about both parties has been placed on the ART Central Register). NSW Health will ensure that this intermediary service will have relevant experience in providing counselling and linkage services.</p> <p>The Government does not support establishing a new stand-alone agency to manage the register and provide these support services. The Government is proposing alternate means to deliver some of the recommended services, whilst still addressing the need for sensitive and specialised service delivery that prompted the recommendation.</p>

Recommendation	Government response
<p>2. The Committee recommends that in the interim, and as a matter of urgency, the Ministry of Health should engage specialists to liaise with donors, donor conceived people and recipient parents, to facilitate access to identifying information with the consent of all parties.</p>	<p>Supported. The Government supports long-term, rather than interim, measures to achieve greater access to information and to raise awareness of the Register.</p> <p>To help realise the objectives of raising awareness of the Register, (increasing both voluntary registrations and applications for access to donor conception information) and facilitating access to information on the Register, NSW Health will:</p> <ul style="list-style-type: none"> • carry out an advertising campaign to raise awareness of the Register (including the Voluntary Register), and • coordinate support services for donors, donor-conceived people, and recipient parents, including referral to an intermediary and support service if a match occurs (that is, where identifying information on both parties has been placed on the ART Central Register, either voluntarily or through the mandated collection of that information).
<p>3. The Committee recommends that the donor conception management agency, once established, collect all donor conception information from assisted reproductive technology clinics and enter it into a secure Register of donor conception information. This Register, once established, should comply with relevant National Health and Medical Council Research guidelines with reference to security and privacy provisions.</p>	<p>The Government supports the desired outcome of secure but accessible storage of information about donor conceptions that occurred prior to 2010. It acknowledges that the information collected may be of variable quality, but nonetheless recognises the potential value of this information to those affected.</p> <p>The Government supports the objective of having pre-2010 information centrally stored. The Government's preferred approach is to collate this information by requiring ART providers to compile and submit pre-2010 donor conception information to NSW Health in a consistent form. This approach has recently been proposed by Victoria in the Assisted Reproductive Treatment Further Amendment Bill 2013 (Vic). The Government will consult ART providers on this approach to collating information in a single, central location, and to inform consideration of the best way in which the collation process should proceed. NSW Health will lead this consultation, and will also consult with donors, donor-conceived people and their parents on any alternative means that are being considered.</p>

Recommendation	Government response
<p>4. The Committee recommends that, as a matter of urgency, the Attorney General amend the <i>Assisted Reproductive Technology Act 2007</i> to make it an offence to destroy, tamper or falsify any donor conception records.</p>	<p>Support in-principle, but consultation and further consideration is required. The Government supports the underlying policy rationale of this recommendation, which is to ensure that donor conception records are not destroyed, tampered with or falsified. The <i>Assisted Reproductive Technology Act 2007</i> already has a penalty for the appropriate retention of records of ART procedures from 1 January 2010 onwards.</p> <p>In considering the best means to provide the appropriate level of protection to pre-2010 records the Government will consult those potentially affected. This will inform whether the criminalisation of this conduct is the best means of ensuring the security and integrity of donor conception information. NSW Health will lead this consultation as it is the Minister for Health that is responsible for the <i>Assisted Reproductive Technology Act 2007</i>.</p>
<p>5. The Committee recommends that the new donor conception management agency implement procedures that allow those individuals conceived before 1 January 2010 to access non-identifying information about their donor, regardless of whether or not the donor consents to such information being released.</p>	<p>Supported. The Government recognises the importance of this information to many donor-conceived people in identifying their biological origins. The Government supports individuals conceived before 1 January 2010 being able to access non-identifying information about their donor without the donor's consent.</p> <p>This access will be provided whether or not this information is collated and centrally stored or retained by ART providers. However the legislative amendments to implement these access provisions will need to be the subject of consultation with stakeholders. NSW Health will lead this consultation.</p>
<p>6. The Committee recommends that the new donor conception management agency implement procedures that allow those individuals conceived before 1 January 2010 to access identifying information about their donor where the donor consents to such information being released.</p>	<p>Supported. The Government supports individuals conceived before 1 January 2010 being able to access identifying information about their donor with the donor's consent.</p> <p>This is the consent-based model that the Committee recommended. The Government agrees that it strikes an appropriate balance between the rights and interests of donor-conceived people, who seek information regarding their biological parentage and genetic history, and past donors, who donated on the condition of anonymity.</p> <p>The legislative amendments to implement these access provisions, whether the material is collated and centrally stored or remains with ART providers, will need to be the subject of consultation with stakeholders. NSW Health will lead this consultation.</p>

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<p>7. The Committee recommends that the new donor conception management agency implement procedures that enable the parents of a donor conceived person [conceived prior to 2010] to access non-identifying information about the donor regardless of the donor's consent on behalf of their child or/and until the child reaches 18.</p>	<p>Supported. The Government supports the parents of a donor conceived person (conceived prior to 2010) being able to access non-identifying information about the donor, regardless of the donor's consent, on behalf of their child until the child reaches 18.</p> <p>The legislative amendments to implement these provisions will be consulted on further.</p>
<p>8. The Committee recommends that, for those individuals conceived before 1 January 2010, the new donor conception management agency implement procedures that enable the parents of a donor conceived person to access identifying information about the donor, where the donor consents to such information being released, on behalf of their child or/and until the child reaches 18.</p>	<p>Supported. The Government supports the parents of a donor conceived person (conceived prior to 2010) accessing identifying information about the donor, where the donor consents to the information being released. Parents will be able to access this information on behalf of their child until the child reaches 18.</p> <p>The legislative amendments to implement these provisions will be consulted on further.</p>
<p>9. The Committee recommends that the new donor conception management agency implement procedures to ensure that the donor and the donor conceived person's siblings have access to:</p> <p>a) any information that the donor conceived person has consented to being placed on the Register of donor conception information and</p> <p>b) further information, if the Registrar is of the opinion that the contact is justified in order to promote the welfare and best interests of one or more of the persons concerned.</p>	<p>Support 9(a). The Government supports donors and the donor conceived person's siblings having access to any information that the donor conceived person has consented to being placed on the Register.</p> <p>The legislative amendments to implement these provisions will be consulted on further.</p> <p>9(b) is supported in that the Government recognises that there may be instances in which the Registrar should use their discretion in determining whether contact is justified. This discretion will be subject to a more specific and objective set of considerations, to be provided for in legislation.</p>
<p>10. The Committee recommends that the new donor conception management agency operate the Register of donor conception information on an active, or consent release based approach, to best facilitate access to donor conception information.</p>	<p>The Government supports the proposal for a consent-released based approach to the release of information. The proposal for the Register to be operated on an 'active' basis is also supported insofar as NSW Health will:</p> <ul style="list-style-type: none"> • engage a specialist service with relevant experience to provide an intermediary and support service for donors and donor conceived adults if a match occurs, and • develop information pamphlets and provide information on the NSW Health website on how to access support services.
<p>11. The Committee recommends that, as a matter of urgency, the Ministry of Health conduct an advertising campaign to raise awareness of the Voluntary Register.</p>	<p>Supported. This will be part of a general awareness-raising campaign to be conducted by NSW Health.</p>

Recommendation	Government response
<p>12. The Committee recommends that the services provided by the agency established to manage the Register of donor conception information include public awareness campaigns, community education, intermediary support, counselling, DNA testing, and the facilitation of contact where this is desired by both parties.</p>	<p>Supported in part. The Government recognises that donor conception information must be managed in a sensitive and holistic way. NSW Health will therefore:</p> <ul style="list-style-type: none"> • coordinate support services for donors, donor-conceived people, and recipient parents, including an intermediary and support service, if a match occurs (as outlined in the above recommendations), • develop information pamphlets and provide information on the NSW Health website on how to access support services, and • review the demand for, and adequacy of, donor conception support services in the next statutory review of the <i>Assisted Reproductive Technology Act 2007</i>. <p>The Government will not be providing DNA testing for donors or donor-conceived people. The Government will however monitor the demand for this service.</p>
<p>13. The Committee recommends that the agency established to manage the Register of donor conception information conduct an advertising campaign to raise awareness of the Register and associated services available, such as intermediary support, counselling and DNA testing.</p>	<p>Supported. The Government recognises the value of the support services identified. NSW Health has committed to awareness raising of the Register. Due to the complexities and specialisations related to the other services, Government will consult, particularly with existing providers, to ensure the most cost effective service provision.</p>